

## **“The seldom heard”- Using evidence to inform patient feedback programmes**

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What does one do while visiting New Zealand on holiday? Well present a seminar at Auckland DHB and the School of Nursing, University of Auckland of course! While visiting in July **I shared some of the patient experience research that I lead** in my shared position between a large health provider (NHS Tayside) in the north east of Scotland and the Centre for Person-centred Practice Research, Queen Margaret University, Edinburgh.

I have had an interest in this area for over 10 years as a key feature of health care quality. Much effort over the last 2 decades has been made to measure and publish patient experiences of care and to build such performance data into regulatory and at time payment schemes. It has been suggested that the public reporting of patient experience will enhance patients’ experiences through desire for management teams to maintain reputation and through enhancing choice. Yet these have not been systematically realised and care experiences continue to vary between and within countries.

Methodological limitations of patient surveys withstanding **I see there are 3 main issues associated with patient experience programmes.**

The first is the lack of attention paid to hearing from all patients; the second is the varied responses of staff when they receive patient feedback and the third is the positivistic approach often taken to understanding the impact of patient experience in any health care system.

**Until recent years many patients have been excluded from research and from service initiatives aimed at understanding and/or improving patients’ experiences of care.** Often those that go unheard are termed the “minority” and /or “hard to reach”. However, these people, termed the “seldom heard” may be so because us, as researchers continue to use a limited set of tools and methods to understand their experiences. Our hospital inpatient populations are comprised of those whose first language is not English, those with visual impairments, hearing impairments, language pathologies or cognitive impairment. Far from being the minority, collectively, they are the majority. They also tend to be the most vulnerable in terms of being able to influence the care they receive and thus; are in most need of our assistance to provide feedback that we can learn from.

People with language pathologies or cognitive impairment can share their experiences when methods are appropriately co-designed or adapted to suit. Work led by Professor Jan Dewing in Queen Margaret University, called “Listen and Learn” has demonstrated that older people can effectively engage with older patients in acute settings to understand their care experiences. We also know that those individuals with literacy difficulties can use existing methods such as the routine patient experience surveys if modes of administration are altered. In NHS Tayside we are working in partnership with the Centre for Person-centred Practice Research in Queen Margaret University on 2 research projects – one to examine what it takes to run a patient experience programme at scale with a range of methods suited to key patient

groups and the other to examine how patients with cognitive impairment can be involved in patient experience feedback processes.

**Our cognitive impairment project has highlighted that patients are often much more capable of providing feedback than previously perceived by those around them** and the interaction allows the data collector to both hear from the person and collect observational data that is useful in understanding the quality of care experiences.

We have also found that real time feedback is the most suitable method for this group and while providing information that can support systematic improvements it can also support “in the moment” opportunities to enhance understanding of each person’s situation and thus immediately enhance their care. Our literature review and interview study with consultant nurses and allied health professionals across Scotland also highlights that the lack of tools and methods to understand the experiences of people with cognitive impairment is a collective concern among professionals and academics but has had little attention.

Our “at scale” project and a previous literature review (Baldie et al, 2017) has taught us a few things about how to enhance clinical teams’ capabilities to effectively respond to feedback they receive. **If you want to support clinical teams to acknowledge, carefully consider and respond positively to patient feedback you need to:**

1. Include them in choosing valid and reliable tools and methods to minimise critique of validity and reliability of findings
2. Invest in data management processes and systems to minimise delays in feedback to staff and to present data in ways that are easily understood and interpreted by staff
3. Ensure you ask questions of patients that practitioners know are of importance to patients and they have some influence over
4. Support staff to see both patient scores and patient comments and help them explore their affective responses before analysing their cognitive response. Clinical teams want to provide excellent care but can be disempowered by systems they work in. Providing conditions in which they can unsurface their frustrations and the opportunities they have to behave in more empowered ways releases potential for affecting change. we have found that is best supported with transformational facilitation and we are building internal capacity for such facilitation in all clinical teams through foundation practice development schools delivered by International Practice Development Collaborative.
5. Ensure a collective vision and values associated with patients’ experiences so each team has a shared understanding of what they wish patient feedback to be
6. Remove the burden of collecting patient feedback from frontline staff – this both results in data being collected at reliable intervals and reduces potential bias that exists when patients consider providing patient feedback to their care team. We have done this by engaging and developing volunteers, mainly from our medical school but also from other walks of life. We are about to recruit from our nursing school and we are offering this role as a routine volunteering role across all our hospital sites.
7. Consider our patient population characteristics and match our data collection methods to their capabilities and preferences.

**Lastly, I have some concerns about understanding impact of patient feedback in systems.** Much research investigating the impact of feedback on care experiences has examined it as a linear and causal relationship with key assumptions that feedback to

practitioners will lead to a recognition for change and then changes will take place, resulting in enhanced experiences. A realist review and evaluation of the use of feedback in general practice has highlighted that this linear relationship rarely exists. Instead a range of contextual factors make this more or less likely and patient surveys' positive skewness and limited discriminatory capability mean that scores can often remain unchanged despite positive changes in practice processes or staff behaviours. We need therefore, as researchers to consider wider views of impact including staff reports of improvement efforts; consideration of trends in patient narrative content; observed changes in practice (by professionals or patients); changes to staff morale and attitudes towards quality improvement and patient experiences in particular.

This is a complex practice and research area but we need to work systematically in health services to find and implement processes for regularly understanding patients' experiences. Taking a one size fits all doesn't work; at scale approaches need to have sufficient flexibility for individual contexts and understanding of impact needs to be context specific. All too often organisations spend massive effort systematically collecting team's improvement efforts; only adding to the bureaucracy of governance. We need instead to continually improve experiences through enhancing opportunities for learning and sharing across systems so teams can learn from each other how experiences can be enhanced.